



# FACTORS INFLUENCING THE PERCEIVED PRIORITY OF TB IN INDIA

<sup>1</sup>Professor D. Bhatnagar

<sup>2</sup>Dr J. Almeida (Editors Summary)

<sup>1</sup> Professor of Organizational Behaviour, Indian Institute of Management,  
Ahmedabad, India

<sup>2</sup> Global Tuberculosis Programme, WHO, Geneva, Switzerland

This document is not issued to the general public, and all rights are reserved by the World Health Organization (WHO). The document may not be reviewed, abstracted, quoted, reproduced or translated, in part or in whole, without the prior written permission of WHO. No part of this document may be stored in a retrieval system or transmitted in any form or by any means - electronic, mechanical or other - without the prior written permission of WHO.

The views expressed in documents by named authors are solely the responsibility of those authors.

Ce document n'est pas destiné à être distribué au grand public et tous les droits y afférents sont réservés par l'Organisation mondiale de la Santé (OMS). Il ne peut être commenté, résumé, cité, reproduit ou traduit, partiellement ou en totalité, sans une autorisation préalable écrite de l'OMS. Aucune partie ne doit être chargée dans un système de recherche documentaire ou diffusée sous quelque forme ou par quelque moyen que ce soit - électronique, mécanique, ou autre - sans une autorisation préalable écrite de l'OMS.

Les opinions exprimées dans les documents par des auteurs cités nommément n'engagent que lesdits auteurs.

## **Factors Influencing the Perceived Priority of Tuberculosis in India**

### **Editor's Summary and Recommendations for Action**

This study assessed the priority attached to TB by various important actors in India, and made recommendations for action. The three main groups of stakeholders considered were:

1. Programme "providers" (the government system)
2. Programme "recipients" (TB patients and the community)
3. "Watchdogs" (media, autonomous organizations).

Discussions (structured and semi-structured), questionnaire surveys, patient interviews, and secondary sources of information were used. Views were sought from the apex of the national TB programme down to the grassroots. Further, views from an RNTCP (Revised National TB Control Programme) pilot project were compared to those from a nearby non-RNTCP district.

TB was found to have a low priority compared to other diseases. Funding was disproportionately low, senior programme leaders did not remain in place for long, health staff were pressured by non-TB activities. Patients experienced indifferent programme delivery. The visibility of TB in the media was low.

A more detailed look highlights several findings. The budget for health within the national plan has been declining from over 3% in the first five-year plan to 1.73% at present, while the budget for family welfare has increased several-fold. Health does not figure prominently in political debates, nor in election manifestos or pre-election promises.

TB has a smaller central budget than malaria, or leprosy, or blindness, or AIDS. Only guinea worm, among the priority communicable diseases, gets less. Negative expectations about the TB programme tend to be self-fulfilling. The missionary zeal of a leader takes time to trickle down to the health workers, and there has been little chance of this happening while leadership has changed hands frequently. The potential of guidelines and training alone to ensure results has been somewhat overestimated. In these circumstances, even DOTS might fail.

The visibility of TB in the media has been near zero. In the year ending May 1996, jaundice, plague, malaria and AIDS each had several articles in the Ahmedabad edition of a leading national newspaper. TB had no articles. Even diabetes had three articles. The media and the TB programme appear to have ignored each other.

Questioning of one group of 21 government doctors attending a TB course in Gujarat showed that they considered malaria and diarrhoea much more important than TB, for public health. They perceived TB as enjoying only moderate to low priority at the central and state

levels. They themselves believe that diarrhoea and AIDS should receive higher government priority than TB because of high mortality. The RNTCP was perceived by them as being less important and successful than polio, neonatal tetanus and leprosy programmes.

In a non-RNTCP area District TB Centre-based programme, patients were reluctant to admit that they had TB, because they feared stigma, and they preferred not to discuss the disease in the presence of family or neighbours. This was more so in urban than in rural areas. Family support for treatment was more frequent among cured patients than among those who had defaulted. More cured patients had to borrow money as a consequence of the disease. The time spent by patients and care-givers on attending the distant hospital for treatment was a source of frequent complaint. The main reasons given for default were "feeling better" and "long distance to the TB clinic".

The RNTCP pilot project site revealed some similar and some different views among patients. The perception of stigma was again greater in urban than in rural areas. Two-thirds of patients received home delivery of medicines. Default was attributed by the patient mostly to a feeling of improvement, or to side effect of drugs, or to economic problems. Distance to the TB clinic did not feature among the reasons for default.

Health workers in the RNTCP typically spent only half an hour per week on TB activities. Their most prominent complaints included the time "wasted" in reaching distant patients, fear of catching TB, and difficulty in making their patients understand instructions. Home delivery of treatment was, remarkably, blamed for irregular treatment: health workers claimed that patients became passive and indifferent to treatment as a result of home delivery. Most health workers claimed that their patients could be trusted to take the medicines. Many health workers found the TB work rewarding, especially the appreciation from people in the community, and most did not favor a monetary incentive for TB work.

### **Recommendations**

Several recommendations were made for improving the situation.

1. Since most TB patients do not read or speak English, the key messages on patient identity cards and TB treatment cards should be in the local language.
2. Since motivation of health workers is crucial for success, good performance should be recognized. This should be accomplished through devices such as certificates, public felicitation in functions organized by local leaders, interviews with popular workers on local television, and other such innovative approaches developed locally.
3. Since local innovation consistent with overall programme guidelines can improve results, field level managers should be encouraged to overcome local problems through innovation.

4. Since verbal and unspoken signals indicate to programme staff the priority attached to TB, key decision makers need to publicly signal the priority of TB. This can be achieved partly by ensuring stable leadership for the TB programme.
5. Since the public is largely unaware of the magnitude of the TB problem (worsened by increasing HIV prevalence), and of the past successes with the DOTS strategy in other countries, a public information campaign should be launched. This should not, however, belittle the enormous efforts being put in by the government machinery, nor hurt national sensibilities. The main thrust of the campaign would be that the time for action is now.
6. Since TB is "disowned" by the people, it needs to be raised to the status of a people's programme through involvement of presently excluded actors, such as private practitioners, medical associations, private voluntary organizations, local industry, the media, opinion leaders, educational institutes. The government should adopt the people-involvement measures which have worked in the case of other government services (railways, post etc).
7. Since initial enthusiasm often gives way to complacency and indifference among the health personnel, the funding for the programme should be split into instalments which are tied to performance. Performance reviews should include external evaluation by groups constituted by the donors: to move beyond "expected answers".
8. Since TB carries a stigma which influences the regularity of treatment, the public should be informed that TB is curable. This should be accomplished through the media (especially television) and through piggy-backing messages on other programmes such as the literacy campaign.
9. Since patients often do not know that cure is different from symptomatic relief, or that interruption of treatment can threaten their lives, patient education deserves much more attention. The initiation of treatment should be designed to give patients faith in the treatment and indicate their responsibilities in achieving cure. In areas where free and effective diagnostic and treatment services are available, the media should be used to inform people where TB services are available, and educate them about the need for uninterrupted treatment.
10. Since the patient's family members often have misconceptions about TB, and since emotional support from the family influences regularity of treatment, the family members should be educated about the need to encourage the patient during treatment.
11. Since many TB patients go to private providers, and since private voluntary organizations have substantial untapped capacity, these actors should be involved in the RNTCP.

Dr. Joël Almeida,  
GTB/TRS, WHO Geneva.

## CONTENTS

## SUMMARY, 3

1. INTRODUCTION, 4
- 2.0 STAKEHOLDERS, 4
  - 2.1 The Programme Provider, 4
  - 2.2 The Programme Recipient, 5
  - 2.3 The Tuberculosis Watchdogs, 5
3. METHODOLOGY, 5
4. TUBERCULOSIS: THE TREATMENT PROVIDER, 5
5. TUBERCULOSIS PRIORITY IN MEDIA, 11
- 6.0 PROGRAMME DELIVERY: STAKEHOLDERS AT THE FIELD LEVEL, 13
  - 6.1 Relative Priority of Tuberculosis: Perceptions of Government Doctors, 13
  - 6.2 Programme Delivery: Experiences of Patients, 18
    - 6.2.1 District Tuberculosis Centre, 18
    - 6.2.2 Experiences of Patients in Urban Areas, 19
      - 6.2.3 Pilot Project Site, 21
        - 6.2.3.1 Patients, 22
        - 6.2.3.2 Health Workers, 23
7. SUMMARY AND CONCLUSIONS, 26
8. ACHIEVING GREATER EFFECTIVENESS: SOME SUGGESTIONS AND ILLUSTRATIVE STEPS, 26

## ACKNOWLEDGEMENTS, 29

## REFERENCES, 30

## APPENDICES, 31

1. Questionnaire for Government Doctors, 31
2. Questionnaire for TB Patients, 34
3. Questionnaire for TB Health Workers, 36



# **Factors Influencing the Perceived Priority of Tuberculosis in India**

## **Project Report**

### **SUMMARY**

The objective of this study was to understand the priority attached to tuberculosis in India by the major stakeholders in the National Tuberculosis Programme, to explore the underlying factors, and to suggest illustrative steps to enhance the effectiveness of the programme delivery.

Major stakeholders were broadly grouped into three categories: the programme providers (the entire government system involved in the design and delivery of the programme, starting with the health ministry at the central government to the health workers at the field level), the programme recipients (patients as well as community at large), and the tuberculosis watchdogs (including the not-for-profit organisations such as the Tuberculosis Association of India and Foundation for Research in Community Health, as well as the media). The perceived priorities of stakeholders were explored through a combination of approaches.

Methodology included discussions with programme functionaries from the apex level to the grassroots level, structured and semi-structured interviews covering all the stakeholders, questionnaire surveys of priorities of government doctors and health workers, and the experiences of tuberculosis patients, perusal of relevant documents, research reports, and newspaper reports, etc.

Our analysis showed an overall low priority for tuberculosis. It manifested itself in a variety of ways: from low plan allocations for tuberculosis among the communicable diseases, and frequent change of the senior-most functionary in the tuberculosis division at the central level, to a relatively-low importance attached by the government doctors, and competing priorities and pressures for the health workers at the field level. Patients' experiences reflected the fallout in terms of indifferent programme delivery. Perusal of the electronic and print media indicated that there was tremendous scope to use this powerful tool for awareness-building about tuberculosis among the larger community in general and for giving specific inputs and message of hope to people suffering from tuberculosis in particular. Our report concludes with suggestions and illustrative steps for enhancing the effectiveness of the Revised National Tuberculosis Programme in India.

## 1. INTRODUCTION

The present report is the outcome of a project undertaken to understand the factors that determine the perceived priority being attached to tuberculosis in India. Specifically, the objectives were as follows:

- To understand the priorities being attached to tuberculosis by major stakeholders in the National Tuberculosis Programme;
- To understand the factors responsible for such priorities;
- To get a feel about the actual status of the present programme realities in the field;
- To suggest illustrative steps in terms of achieving greater effectiveness for the programme delivery.

## 2.0 STAKEHOLDERS

For a disease like tuberculosis which continues to be rampant in India, which claims the life of an Indian every minute, and is believed to infect about 40% to 50% Indians, it is difficult to decide who is NOT a stakeholder! As present and/or potential hosts to the tuberculosis bacterium, all Indians are stakeholders. And the stakes multiply as the sceptre of the tuberculosis-HIV combination moves rapidly closer from a haunting fear to a dreadful reality. So for our purpose, the first category of stakeholders are the common people. Then as we move to greater formalisation and specificity regarding the suffering from and treatment of tuberculosis, the variety of stakeholders can broadly be grouped into three categories:

- the treatment provider
- the treatment recipient, and
- the tuberculosis watchdogs.

These categories, as used in the present project, are spelt out below.

### 2.1 The Programme Provider

For our purpose, this category has been used in a broad sense. At the diagnostic stage, our focus has been on the public health care system. The treatment provider as a stakeholder includes not only the doctor who diagnoses the disease and treats the patient, but the entire government system involved in the design and delivery of the Revised National Tuberculosis Programme, from the central government where relative priorities are assigned to public health in the first place, to the tuberculosis programme within the ministry of health where other diseases and health programmes enjoy competing priorities, down the line to the state government and the district administration, and finally the primary health centre in rural areas which has the responsibility of delivering the programme at the grassroots level. Our analysis begins with a focus on these different players within the 'treatment provider' category. The private practitioners and the not-for-profit organisations engaged in the treatment of tuberculosis patients also come under this category, but our present focus is on the government system.

## **2.2 The Programme Recipient**

To us, the people at large, but specifically the potential, suspected, or confirmed tuberculosis patient is the key stakeholder for whom the entire programme is meant. While discussing the perceived role and contribution of providers, we have tried to keep the recipient at the centre stage. Although as of now the attention in the programme is focused primarily on the patient, it needs to be broadened to include the education of general public, too, in its ambit.

## **2.3 The Tuberculosis Watchdogs**

Autonomous agencies, and health research foundations whose objectives include monitoring tuberculosis management in the country are included. In our project, these agencies were represented by the Tuberculosis Association of India, New Delhi and the Foundation for Research in Communicable Health, Bombay. Also, shapers of public opinion such as the mass media are included in this category which for want of a better term is labelled the tuberculosis watchdogs.

## **3. METHODOLOGY**

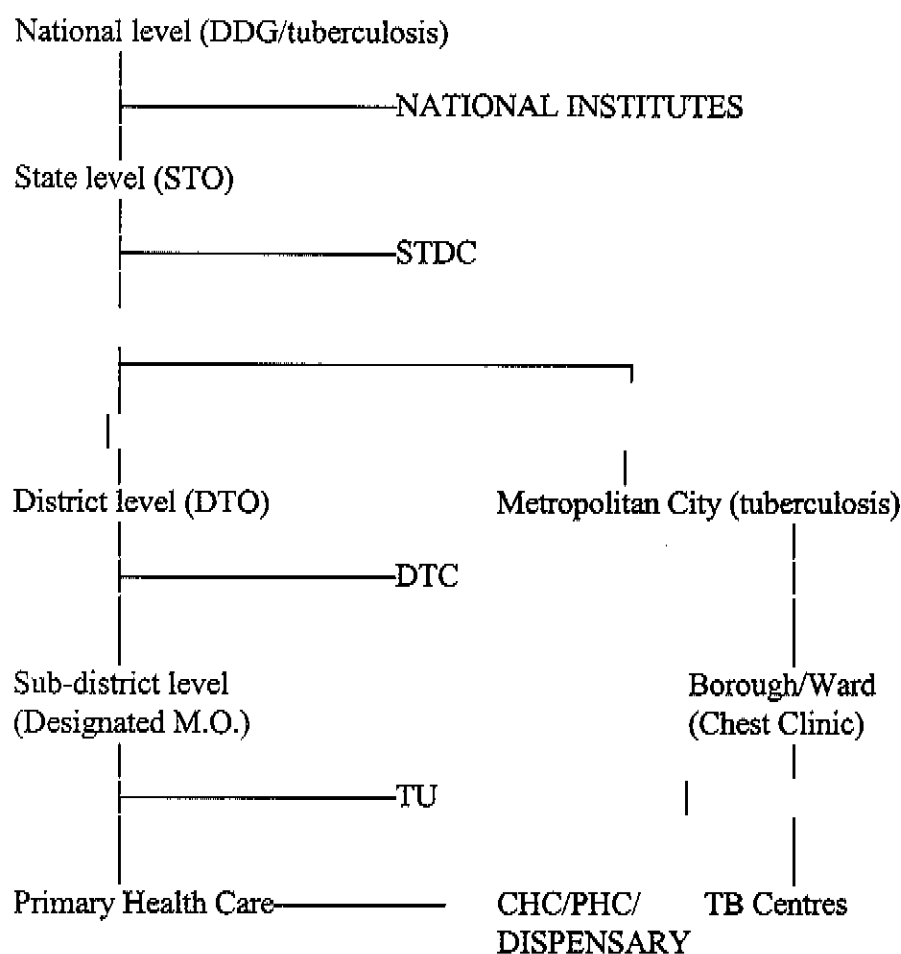
A variety of methods were used for gaining insights. These included unstructured and semistructured interviews with government officials at the central, state, and the district levels; discussions with tuberculosis experts, members of NGOs engaged in treatment of and research on tuberculosis, and veteran practitioners, field functionaries and patients; visits to field sites; questionnaire surveys; and, perusal of newspapers reports, Government of India reports, tuberculosis programme documents, research reports, etc.

Special attention was paid to the programme delivery to understand the experiences and perceptions of the programme deliverer (the health worker) and the programme recipient (the tuberculosis patient). In addition to interviews, survey questionnaires were constructed for health workers, tuberculosis patients and doctors. The questionnaires used for the government doctors, the tuberculosis patients, and the health workers are presented in Appendix 1, 2, and 3 respectively. The purpose in the first two cases (patients and health workers) was to capture respondents' experiences, feelings, and practices. In the case of the doctors, we wanted to know their perception of relative priority attached to the tuberculosis programme. Doctors were not told that tuberculosis was the main interest of the survey; it was randomly combined with other diseases all of which they were asked to rank order in terms of their relative importance to public health. The field study was carried out at a DOTS pilot project site in Western India.

## **4. TUBERCULOSIS: THE TREATMENT PROVIDER**

If the National Tuberculosis Programme (NTP) can in its entirety be viewed as the "Treatment Provider", which besides prevention, is a major objective of the programme, then we can examine the perception of the priorities at different levels.

In a nutshell, the NTP has the following structure<sup>1</sup>:



As is clear from the above, NTP has not included two major categories of treatment providers namely private medical practitioners and NGOs in its gameplan. The earlier programme design was based on contemporary realities prevalent at that time and, probably for want of a comprehensive review later, the subsequent changes in the design and structure have not incorporated later realities such as the phenomenal growth of private doctors especially in the urban areas, and the emergence and role of NGOs as important players who could be profitably involved at different stages of programme delivery. Thus, a major assumption that could be inferred from the present programme design of RNTP is : "As treatment providers, we are the only major stakeholder and we can do it alone". Various researchers and other stakeholders have started questioning the validity of this assumption (Pamra, 1995; Uplekar, 1995). Also, as a monolithic structure, the programme offers a standard design for uniform implementation across different geographic areas, ignoring regional and local variations in the spread of the disease, patient profile and needs, different socio-economic realities, attributes of actors etc. The

<sup>1</sup>. "Operational Guideline for Revised National Tuberculosis Control", Directorate General of Health Services, Nirman Bhavan, New Delhi, 1995, p.3.

result is an elegant design which may work under some conditions but not necessarily in all, but which does not offer sufficient scope and encouragement for innovation to meet specific local needs.

In the following section, we have presented an analysis of the perceived priorities at the central, state, district, and the PHC levels.

At the national level, the Ministry of Health, Directorate General Health Services has a team at the Tuberculosis Division, headed by the DDG/tuberculosis. The NTP is responsible for "technical and operational norms and procedures; planning, monitoring and evaluation; ensuring regular supplies and adequate training of personnel; quality assurance; obtaining and analysing data on surveillance and programme implementation; obtaining sufficient resources for the programme and coordinating activities of different institutions" <sup>2</sup>.

If we start by examining the priorities at the apex level itself, the first visible indicator of priorities is the relative allocation of funds to particular activities at the central government level. Admittedly, these allocations represent a partial picture; a variety of reasons such as expected financial support from outside agencies may influence the allocation decisions. Nonetheless, the allocations do give some idea about the relative priorities! Table-1 gives a historical picture of the relative priority attached to the health sector under different plan periods.

---

<sup>2</sup>. "Operational Guideline for Revised National Tuberculosis Control", Directorate General of Health Services, Nirman Bhavan, New Delhi, 1995,p.2.

Table-1

## Investments in Different Plan Periods

(Rupees in crores)

Period	Total Plan Investment	Health	Family Welfare	Water Supply & Sanitation
I Plan (1951-56)	1960.00	65.20 (3.327)	0.1 (.005)	N.A.
II Plan (1956-61)	4672.00	140.80 (3.014)	2.20 (.047)	N.A.
III Plan (1961-66)	8576.00	225.00 (2.624)	24.90 (.290)	10.70 (0.125)
Annual Plans (1966-69)	6625.40	140.20 (2.116)	70.50 (1.064)	102.70 (1.550)
IV Plan (1969-74)	15778.80	335.50 (2.126)	284.40 (1.802)	458.90 (2.908)
V Plan (1974-79)	39322.00	682.00 (1.734)	497.40 (1.265)	971.00 (2.469)
1979-80 Outlay	11650.00	268.20 (2.302)	116.20 (0.997)	429.50 (3.687)
VI Plan (1980-85)	97500.00	1821.05 (1.868)	1010.00 (1.036)	3922.02 (4.023)
VII Plan (1985-90)	180000.00	3392.89 (1.885)	3256.26 (1.809)	6522.47 (3.624)
Two Annual Plans (1991-92)	137033.55	2253.86 (1.645)	1805.52 (1.318)	4427.29 (3.231)
VIII Plan (1992-97)	434100.00	7575.92 (1.745)	6500.00 (1.497)	16486.93 (3.798)

(Figures in parentheses denote percentage.)

As the table shows, the plan allocations for health started by being 3.327% of the total plan investment in the first five year plan. By the end of the fifth five year plan, the ratio of health to total plan investment had successively reduced to 1.734%, whereas family welfare had increased from .005% to 1.265% in the same period! The sixth and seventh five-year plans saw a further decline in the relative importance of health in the national priority, till in the 8th plan, health (@1.745% of the total plan investment, and a close second to the lowest priority @ 1.734 in the 5th plan) enjoys one of the lowest priorities among all the five-year plans. These figures compare unfavourably even with small developing countries like Ghana and Congo which allocate 7.3 and 6.1 per cent respectively of the national budget to health (Ray, 1996). That politically, health is not a major issue is clear from the fact that it does not figure high on politicians' priorities: it forms part of neither political parties' election manifestos, nor of pre-election promises of most individual candidates.

To conclude from the above analysis, the relative importance of public health has seen a consistent decline in the priorities of the policy makers at the central government level. One can only speculate on whether a sector seeing gradual erosion of its importance over the years can attract the keenest administrative talent willingly at the top. Moreover, seeing its declining importance in relative terms, the most committed of the health chiefs may find it tough to

sustain their enthusiasm for long. For want of both, the political will as well as financial resources, the issue of having conviction and contagious enthusiasm at the top that can inspire and energise the entire health ministry, including the Tuberculosis Division, becomes remote.

Our next question is, within the health ministry, what is the relative priority attached to tuberculosis control.

Once again, going by some recent plan outlays, the picture for tuberculosis does not appear to be encouraging. Table-2 presents outlay for health in the central sector.

Table-2  
**Outlay for Health in the Central Sector**

(Rs in Crores)

Programme/ Scheme	8th Plan Outlay	1992-93		1993-94		1994-95		1995-96 Outlay
		Outlay	Actual Expdr.	Outlay	Actual Expdr.	Outlay	Antici- pated Expdr.	
<b>B. Centrally Sponsored Schemes</b>								
<b>I. Control of Communicable Diseases</b>								
1. Malaria control	425.00 (41.222)	65.00 (34.946)	98.03 (47.346)	110.00 (39.497)	110.54 (47.611)	110.00 (29.487)	167.73 (38.343)	139.00 (32.993)
2. Tuberculosis control	85.00 (8.244)	13.50 (7.258)	27.01 (13.045)	35.00 (12.567)	17.19 (7.440)	46.00 (12.331)	46.00 (10.516)	50.00 (11.868)
3. Leprosy	140.00 (13.579)	24.00 (12.902)	33.99 (16.416)	35.00 (12.567)	50.94 (22.048)	94.00 (25.198)	94.00 (21.489)	80.00 (18.989)
4. Blindness	100.00 (9.699)	13.50 (17.258)	17.59 (8.496)	25.00 (8.977)	18.81 (8.141)	40.00 (10.722)	40.00 (9.144)	72.00 (17.0899)
5. AIDS	280.00 (27.158)	70.00 (37.634)	29.71 (14.349)	73.00 (26.212)	33.06 (0.143)	82.55 (22.128)	71.21 (16.279)	80.00 (18.989)
6. Guinea Worm Eradication	1.00 (.097)	-	0.72 (0.348)	.50 (0.179)	0.50 (0.216)	0.50 (0.134)	0.50 (0.114)	0.30 (.071)
7. Plague	-	-	-	-	-	-	18.00 (4.115)	-
Sub-Total	1031.00	186.00	207.05	278.50	231.04	373.05	437.44	421.30

(Figures in parentheses denote percentage.)

As evident from the above table, in terms of resource allocation, which is a dependable indicator of government priorities, tuberculosis control appears to be the least favoured programme within the 'Communicable Diseases' category, except the Guinea Worm Eradication programme! The purpose here is not to speculate about the reasons for this low priority which may be influenced by a variety of considerations, but to highlight its consequences in terms of the actual delivery. Admittedly insufficient fund allocation leads to inadequate delivery; but equally importantly, it gives negative psychological signals to programme functionaries about

the significance the government attaches to the tuberculosis programme. Thus allocation of 8.24% of the total outlay for control of communicable disease in the 8th plan to tuberculosis, compared to 13.58% to leprosy, 27.16% to AIDS, and 41.22% to malaria control gives a clear signal about the relative priority of tuberculosis, and such signals influence perceptions and performance of programmes!

Besides financial allocations, the perceived priority can also be inferred from structural and process characteristics associated with a programme/division. For example, if the senior most designation in a particular division connotes a relatively modest position in the bureaucratic hierarchy, to that extent it not only suggests relatively modest power base of the incumbent to get things done, but also sends an unambiguous signal down the line about the low concern being attached at the highest level to the significance and contribution of that division. Some process-related factors which influence the perceived priority include the stability of the tenure of the division chief and the visibility accorded to the division. Such indicators, particularly when indifferent or negative, can carry an element of the self-fulfilling prophecy: if programme functionaries interpret the structural and processual signals to indicate that theirs is an unimportant programme which is not expected to make much of a dent after all, then indeed their performance can adjust itself to meet those negative expectations!

In the case of the Tuberculosis Division, our data suggest that the signals in the past have been mixed. The upgradation of the position of the senior most NTP manager by two steps to Deputy Director General (DDG/tuberculosis) in 1993 was an unmistakably positive indication of the enhanced importance and priority of the NTP. Going beyond perceptions, in terms of its actual impact, indeed a strong central team assisted by competent support at other levels could revitalise and strengthen the programme. However, some processual signals dimmed the effect of this positive message. Most important of these has been the tenure of the incumbent at the senior most position. So whereas at other levels, efforts are on for developing mechanisms for effective programme implementation and sustenance, frequent changes at the top in the last two years have added avoidable discontinuities. The frequent change of guards tends to confuse and demoralise the dedicated tuberculosis workers occupying different positions. Moreover, such changes have diluted the earlier structural signal about the increased priority of the programme. If the RNTP, like any successful programme, has to derive its sense of purpose, priorities, and inspiration from its leader, then it is obvious that the formal leader has to have an uninterrupted, sufficiently-long tenure in order to offer the same. Moreover, for an integrated programme like the RNTP, which in its present design and structure has to depend on the often overstretched and sometimes apathetic government machinery for programme delivery, leadership can play a pivotal role. Through its visible conviction and missionary zeal, the central leadership can invigorate the programme and invest it with a sense of urgency, challenge and pride. However, for such inspiration and enthusiasm to trickle down, sufficiently long tenure of dedicated leadership at the top is an absolute must. Failure in this regard can portend a low perceived priority of the RNTP and a below par programme performance.

At the apex level, a carefully detailed programme structure has been worked out to implement the Revised National Tuberculosis Programme. "Operational Guideline for Revised National Tuberculosis Control" (1995) clearly spells out programme objectives, strategy, structure and function at different levels, procedures for diagnosis, treatment, drug administration, and

reporting, monitoring, supervision and evaluation system as well as details of the training strategy. A companion volume titled "Technical Guide for Tuberculosis Control" (1995) provides useful information about the disease, complications, kind of laboratory services available, general aspects of chemotherapy, side effects, and HIV and Tuberculosis. Since diagnosis and management of cases from among chest symptomatics calls for 3 sputum smear tests, then extended treatment for 6-8 months, the task of disease management involves, besides diagnosis and treatment, the maintenance of treatment card, laboratory form and laboratory register at the microscopy centre, and tuberculosis register and quarterly reports at the tuberculosis unit. Discussions with some programme officials at the apex level suggested an implicit assumption that once a detailed blueprint incorporating the operational guidelines had been put in place, and people had been trained and assigned their responsibilities in the RNTP, the desired performance would follow. We tried to explore this assumption at the field level.

Tuberculosis watchdogs shared serious concern about the evidently low priority to tuberculosis at the central level. A number of knowledgeable people interviewed by us expressed the feeling that the RNTP does not enjoy deep commitment of the top. Lack of political will, uncertain tenure and resultant partial commitment, and emotional distance from the field realities seemed to be responsible for the low priority. There was a feeling that the looming possibility of tuberculosis-AIDS complication that should compel programme managers to sit up, plan and energise the programme while it was still not too late, had not evoked the expected sense of urgency. There was a feeling that tackling tuberculosis within the existing health services framework with all its strengths and limitations would be as effective\ineffective as that framework, and unless radical steps were taken to revive and bolster the present health system, measures such as DOTS would merely provide, like partial tuberculosis treatment, immediate symptomatic relief, but no cure.

## 5. TUBERCULOSIS PRIORITY IN MEDIA

As general public is an important stakeholder, media plays a key role in spreading awareness about diseases by educating people about the nature and morbidity of a particular disease, health care facilities available for diagnosis and treatment, simple precautionary and preventive measures, etc, so that unfounded fears and stigma based on primitive beliefs can be removed. Sharing with people in a simple and interesting style the basic information about a disease and scientific ways of tackling it is the best social inoculation. Media, print as well as electronic, is a powerful vehicle to do so. In India, there are examples of effective use of electronic media for this purpose, for example, in the case of the pulse polio campaign in the recent past.

We wanted to have some insight into the relative priority of tuberculosis in the print media. For this purpose, we selected a national newspaper, The Indian Express, and looked at the health-related news/articles published in the Ahmedabad edition of the newspaper. We selected one year, from June 1995 to May 1996, to review the newsitems/articles on health. Our research was facilitated by the fact that the local office of the newspaper maintained a 'health file' of its newsitems and articles. Table-3 shows the frequency with which articles on a particular disease appeared in the Indian Express during June 1995-96.

Table-3

Health Related Articles in Indian Express  
(June 1995 to May 1996)

Sl No.	Disease	Frequency
1	AIDS	7
2	Drug Addiction	4
3	Plague	13
4	Mental Disorders	1
5	Jaundice	24
6	Malaria	8
7	HIV	1
8	Diabetes	3
9	Hepatitis	4
10	Asthma	1
11	Falciparum Malaria	1
12	Measles	1
13	Leprosy	1
14	Polio	1
15	Diarrhoea	1

As the above table shows, Jaundice (24 articles) received the maximum attention, followed by plague (13), malaria (8), and AIDS (7). Drug addiction (4), hepatitis (4), and diabetes (3) appeared several times. Asthma, measles, leprosy, polio, and mental disorders received at least one mention. Interestingly, tuberculosis found not a single mention!

Admittedly, a number of contemporary and proximal concerns, such as outbreak of plague in the city of Surat in 1994, recurrent problem of jaundice and the return of malaria in Gujarat in particular might have influenced the above tally, so inferences should be drawn carefully. Also it is possible that because tuberculosis does not erupt in an epidemic form, it does not attract conspicuous attention as a newsitem. Yet the fact remains that a noncontagious, nonepidemic disease like diabetes found a place thrice whereas tuberculosis despite its highly contagious nature did not find a single mention! This exercise highlighted the low priority attached to tuberculosis not only by the print media but also by the programme managers who could have sought the help of the press for awareness building.

Scanning the social advertising messages on the local electronic media confirmed the same. During the pulse polio campaign in January 1996, TV was used extensively and imaginatively. Of late, messages concerning eye donation, and creating awareness about leprosy have started appearing on the small screen. Even for AIDS which warrants sensitive social treatment in the traditional Indian culture, TV spots have started appearing at the prime time. However, this powerful medium has not been used so far to dispel widespread myths about tuberculosis from the public mind, and to equip people to tackle the disease with confidence. It is thus clear that for enhancing the perceived priority of tuberculosis in the minds of the public who as a collectivity are the most significant stakeholder, tuberculosis programme managers need to use the media much more effectively and vigorously.

## 6.0 PROGRAMME DELIVERY: STAKEHOLDERS AT THE FIELD LEVEL

### 6.1 Relative Priority of Tuberculosis: Perceptions of Government Doctors

At the point of programme delivery, doctors constitute an important group of stakeholders. We wanted to know their perceptions of the relative priority of tuberculosis. A questionnaire including tuberculosis as one of the several disease to be studied, so as not to prime the respondents on our central interest on tuberculosis was developed. We sought responses of 21 government doctors who had assembled to attend a training programme on tuberculosis. Results are presented below.

#### Doctors' Priority:

Table - 4A  
Respondent's priority for disease in terms of impact on public health\*

N = 21 (Doctors)

Disease	Priority						
	First	Second	Third	Fourth	Fifth	Sixth	Seventh
AIDS (fq.) %	0	2 (9.52)	3 (14.29)	5 (23.81)	3 (14.29)	4 (19.05)	4 (19.05)
Leprosy %	0	0	0	5 (23.81)	7 (33.33)	1 (4.76)	6 (28.67)
T.B. (fq.) %	3 (14.29)	5 (23.81)	1 (4.76)	1 (4.76)	0	0	0
Malaria %	8 (38.1)	5 (23.81)	1 (4.76)	1 (4.76)	1 (4.76)	0	0
Diarrhoea %	8 (38.1)	7 (33.33)	1 (4.76)	1 (4.76)	1 (4.76)	0	0
Heart Disease %	0	0	2 (9.52)	2 (9.52)	4 (19.05)	9 (42.86)	6 (28.57)
Jaundice %	0	0	5 (23.81)	5 (23.81)	5 (23.81)	6 (28.57)	4 (19.05)

(Percentages rounded off to two decimal points in this and the subsequent tables).

This table shows that 14% respondents personally attached priority 1 to tuberculosis, compared with 38% attaching top priority each to malaria and diarrhoea. The second priority was given to diarrhoea by 33%, and to tuberculosis and malaria each by 24% respondents. Compared to these three diseases, jaundice, AIDS, leprosy and heart diseases received low priority.

Perceived Priority at the State Level:

Table - 4B

**Perceived Priority at the State Level**

Disease	Priority						
	First	Second	Third	Fourth	Fifth	Sixth	Seventh
AIDS (fq.) %	2 (9.52)	0	2 (9.52)	5 (23.81)	4 (19.05)	5 (23.81)	1 (4.76)
Leprosy %	1 (4.76)	0	0	10 (47.62)	6 (28.57)	0	4 (19.05)
T.B. (fq.) %	2 (9.52)	6 (28.57)	11 (52.38)	2 (9.52)	0	0	0
Malaria %	11 (52.38)	5 (23.81)	5 (23.81)	0	0	0	0
Diarrhoea %	5 (23.81)	10 (47.62)	2 (9.52)	3 (14.29)	1 (4.76)	0	0
Heart Disease %	0	0	0	0	1 (4.76)	7 (33.33)	12 (57.14)
Jaundice %	0	0	1 (4.76)	1 (4.76)	8 (38.1)	7 (33.33)	3 (14.29)

Responses presented an interesting picture: 52% respondents felt that the state government attached the top priority to malaria; diarrhoea came next (24% responses); and tuberculosis and AIDS were seen as top state govt priorities by 10% respondents. Twenty nine% respondents thought tuberculosis was the second most important priority and 52% thought tuberculosis was the third priority at the state level! Perceived Priority at the Central Level:

Table - 4C

## Perceived Priority at the Central Level

Disease	Priority						
	First	Second	Third	Fourth	Fifth	Sixth	Seventh
AIDS (fq.) %	3 (14.29)	1 (4.76)	4 (19.05)	5 (23.81)	6 (28.57)	1 (4.76)	1 (4.76)
Leprosy %	0	0	3 (14.29)	7 (33.33)	8 (38.1)	2 (9.52)	1 (4.76)
T.B. (fq.) %	5 (23.81)	7 (33.33)	5 (23.81)	3 (14.29)	1 (4.76)	0	0
Malaria %	8 (38.1)	8 (38.1)	4 (19.05)	1 (4.76)	0	0	0
Diarrhoea %	4 (19.05)	4 (19.05)	4 (19.05)	5 (23.81)	4 (19.05)	0	0
Heart Disease %	0	1 (4.76)	0	0	2 (9.52)	3 (14.29)	11 (52.38)
Jaundice %	1 (4.76)	0	1 (4.76)	0	0	11 (52.38)	4 (19.05)

Compared to the state level, centre was perceived as attaching greater priority to tuberculosis. Responding to the question on the perceived priorities of the central government, 24% respondents thought that the centre attached priority 1 to tuberculosis, while 38% felt that malaria enjoyed the top central priority. Respondents' Recommendations for Central and State Levels:

Table - 4D

## Respondents' Recommendations for Central and State Levels

Disease	Priority				
	First	Second	Third	Fourth	Fifth
Diarrhoea %	10 (47.62)	1 (4.76)	1 (4.76)	4 (19.05)	2 (9.52)
Malaria %	2 (9.52)	7 (33.33)	5 (23.81)	4 (19.05)	2 (9.52)
AIDS (fq.) %	5 (23.81)	4 (19.05)	4 (19.05)	1 (4.76)	6 (28.57)
T.B. (fq.) %	3 (14.29)	7 (33.33)	8 (38.1)	2 (9.52)	1 (4.76)
Leprosy %	0	2 (9.52)	1 (4.76)	7 (33.33)	6 (28.57)
Cancer %	0	0	1 (4.76)	0	0
Jaundice %	0	0	0	2 (9.52)	3 (14.29)
Heart Disease %	0	0	1 (4.76)	0	0
Polio %	1 (4.76)	0	0	0	0

When asked which five diseases should receive the highest priority at the central and state level, 48% respondents voted for diarrhoea, 24% for AIDS, and 14% thought tuberculosis should receive the top priority.

The reasons for giving high priority were high mortality (57%), infectious nature of the disease (19%), incurability (14%), and socioeconomic problems (2%). Two respondents gave no reasons.

Contribution of Organisations:

Table - 4E  
**Contribution of Organisations**

Organisations	Frequencies	Percentage
P.H.C.s	18	85.71
Government Dispensaries	17	80.95
N.G.O.s	7	33.33
Private Practitioners	3	14.29

In response to a question about which organisations are doing useful work in the field of disease control, the Primary Health Centres (PHCs) received the highest support (86%), followed by the government dispensaries (81%), Non-government Organisations (NGOs-33%), and the private practitioners (14%).

The Most Important Government Programmes:

Table - 4F  
**The Most Important Government Programmes**

Programmes	Frequencies	Percentage
Polio Eradication	16	76.19
Neonatal Tetanus Eradication	13	61.91
Leprosy Eradication	9	42.86
R.N.T.P. (T.B.)	6	28.57
C.S.S.M.	2	9.52
N.M.E.P. (Malaria)	3	14.29
AIDS	4	19.05
Guinea Worm Control	5	23.81

Blindness Control Programme	1	4.76
O.R.T. (Diarrhoea)	1	4.76
Cancer	1	4.76
R.C.H.	1	4.76

Finally, when respondents were asked to mention three most important government programmes for disease control, 76% respondents mentioned the polio programme, 62% mentioned the neonatal tetanus eradication, and 43% included the leprosy eradication programme. The Revised National Tuberculosis Programme was mentioned by 29%, which was quite close to the guinea worm control programme (24% respondents).

The purpose of the above exercise was not to carry out an extensive survey, but to get a feel about the perception of the relative priority of tuberculosis in the minds of government doctors. Despite the small sample size, some interesting trends can be discerned. Our data indicates that government doctors see tuberculosis as enjoying a moderate to low priority at the central and state levels. They themselves believe that diarrhoea and AIDS should receive higher government priority than tuberculosis because of high mortality. Lastly, the RNTP is not seen as being as important and successful in disease control as polio, neonatal tetanus and leprosy programmes. Put together, these responses add up to a perceived secondary priority of tuberculosis among doctors at the field level and the perception of the RNTP as a relatively weak programme. This perception assumes further significance in light of the fact that these doctors had especially gathered to attend a programme on tuberculosis and were to some extent psychologically primed for favourable responses towards tuberculosis. Informal discussions with doctors confirmed the above perceptions.

## 6.2 Programme Delivery: Experiences of Patients

As tuberculosis patients are the key stakeholders for whom the RNTP is meant, it was decided to explore their experiences and perceptions at length. We used two sites for this study: a District Tuberculosis Centre and a project site where the DOTS pilot project is on. Details are presented below.

### 6.2.1 District Tuberculosis Centre (DTC)

Our discussions with officials at the DTC suggested that tuberculosis received a low priority at the district level. In meetings of district level doctors, tuberculosis-related issues were often raised last, and the discussion barely lasted beyond five minutes.

For contacting patients, we requested a district tuberculosis centre to randomly select and provide us names and addresses of 100 tuberculosis patients who had completed the treatment recently, and of another 100 patients who had defaulted. Because case holding is a key challenge in successful tuberculosis treatment, it was felt that a comparison of the experiences of the patients who completed the treatment with those who defaulted may provide valuable

clues for improving the cure rate. Locating the patients posed considerable difficulty. Major problems were incomplete address, the patient having moved to some other place not known to neighbours, the patient having returned to his/her village, unwillingness of the patient or the family members to talk about tuberculosis because of social stigma; and in case of a few married female patients, their having returned to their parents' place due to the hostile behaviour of husband and his family members after the wife contracted tuberculosis. In two cases, although the patient's address was correct, the family members pretended that nobody having the patient's name stayed there!

After preliminary interviews with a few patients, a questionnaire was constructed and translated into the local language. Some of the items were taken from a recently-published study (Uplekar and Rangan, 1996). The questionnaire was used along with interviews. We managed to gather responses from 47 patients who had completed the treatment and from 45 patients who were "defaulters".

### 6.2.2 Experiences of Patients in Urban Areas

In the past, probably because of high mortality and the infectious nature of their disease, tuberculosis patients often used to be stigmatised and ostracised. Even members of the middle class, with supposedly higher levels of education and awareness, used to feel inhibited and used to exercise caution in acknowledging that they or a family member had contracted tuberculosis. With greater awareness and the availability of modern drugs promising complete recovery if taken regularly, such attitudes are undergoing a gradual change. However, in the urban areas visited by us, the presence of social stigma could be sensed. Interestingly, it seemed to pervade to a lesser extent in rural areas.

In our project, the patient attitudes and experiences varied a great deal. There were a few patients who did not mind talking openly about their experiences. Some other patients expressed initial hesitation which they could overcome soon as the interview progressed. The majority of urban patients were reluctant to discuss their disease in front of others (neighbours, relatives, etc). Some pretended that they never had the disease, and a few refused to talk which decision had to be accepted with good grace. The interviews were carried out with sensitivity to patients' social and personal concerns.

We noticed a few significant differences in attitudes between the defaulters and those who completed the treatment. The defaulters (Defs) appeared (probably because of their continued distress) to have a less optimistic attitude towards the disease, towards the medication, and towards life in general compared to the cured patients (Cups). Many more Cups than Defs reported receiving continued family support after tuberculosis was diagnosed. Some Defs talked about having been abandoned by their families, about being objects of sympathy and pity, and about the concern of their family members that they should not infect others. Both Cups and Defs reported physical and mental fatigue after contracting the disease, occasional insomnia and loneliness, fear of death, and a desire to get well soon. Patients of both categories talked about several side effects of drugs such as nausea, giddiness, burning sensation in the stomach, headache, diarrhoea, weakness, etc.

Experiences with the doctor:

Many more Cups than Defs reported positive experiences with the doctor. Thus 25 Cups, compared to 16 Defs, thought that they were treated decently by the doctor who told them details about how to take the medicine. Several patients from both categories recalled receiving a message of hope from the doctor that if they completed the treatment, they would recover fully. A few Defs complained of illtreatment and how the doctor did not listen to them. This indicates some relation between the completion of treatment and recall of positive experience with the doctor.

Financial Problems:

Both Cups and Defs mentioned economic hardship. Respondents in each category (20/45 Defs and 16/47 Cups) reported having to borrow money. Two Defs reported that they were out of job and expressed physical inability to go to work. A few had to walk several miles to the hospital to collect their medicine because they could not afford the transport.

Reaching the Hospital:

Many patients expressed difficulty in reaching the hospital as a major problem. They were vocal about how travelling to and fro to collect their medicine wasted a lot of their time; their work got affected; they could not always take time off to reach hospital in time. Several patients observed that they were too weak to travel alone; and the person accompanying the patient too had to waste a lot of time. A few even observed that due to their inability to move alone, they had not been able to go and collect their medicine.

Reminders from the Hospital:

Many defaulters mentioned receiving reminders from the hospital when they had failed to collect the medicine. The suggestion was that if drug distribution could be decentralised to closer locations, default rate could be reduced.

Faith in the Medicine:

The Cups differed significantly from Defs in this regard. Compared to Defs (18/45), many more Cups (43/47) expressed complete confidence in the medicine. Discussions indicated that many Defs had more or less resigned themselves to continued misery, even death. Suspicious about the efficacy of drugs which they had tried, benefitted from, and then abandoned believing that they did not need medication, only to be gripped by the disease again in a more virulent form, they conveyed a deep sense of despair and hopelessness. Without drawing causal inference, but as part of future communication strategy between doctor and patient, heavy emphasis on building patient's faith in the treatment and imparting firm hope that recovery is absolutely achievable and in the hands of the patient makes sense.

### Information about the Disease:

All the patients mentioned receiving information about the disease from the doctor. They were told by the doctor to complete the treatment. A few even mentioned receiving additional information from the staff. Considering the heavy workload on doctors, this was a very positive and encouraging feedback. However, while all the respondents recalled having been TOLD by the doctor to complete the treatment, nobody remembered having been TOLD the consequences in terms of developing drug resistance leading to further complications if they defaulted.

Interestingly, only two patients remembered receiving general information about tuberculosis from the mass media. The public health service (PHS) was cited as the source by 28 Defs and 25 Cups. Formal education was cited by 5 Defs, and none of the Cups. The private practitioner was recalled by 2 Defs and 10 Cups. Community, neighbours, and friends were seen as the primary source of information by 8 Defs and 6 Cups. This suggests the important role played by the PHS in general and the role of private practitioners particularly in the case of Cups.

### Reasons for Stopping Medication:

The defaulters were asked why they discontinued the medication. Reasons were quite revealing! They included the following:

As I started feeling better, I stopped taking the medicine because I thought I had recovered (18).

Because of the long distance from the tuberculosis clinic, I could not go regularly to collect the medicine (11).

The side effects of the drugs made me very uncomfortable (7).

I felt I could not go to the hospital alone (5).

I felt too lazy to go and collect the medicine regularly (4).

I did not like the way I was treated at the hospital (4).

I got bored of the long treatment (1).

Some patients had indicated multiple reasons.

Evidently, they did not know that symptomatic relief did not mean cure; and they were not aware of the danger of developing multi-drug resistance. In other words, they did not know adverse personal consequences of discontinuing the treatment. Many patients mentioned that due to various discomforts, they used to reduce the dosage arbitrarily.

To sum, our interactions with patients showed that though the patients were interested in recovery, their ignorance of the fact that symptomatic relief did not mean cure and their

ignorance about the negative consequences of interrupting the treatment - both of which could be tackled through an effective communication strategy, were some of the major factors leading to default. Added to these were problems associated with the long-drawn nature of treatment, difficulty in drug procurement, despondency and negative side-effects of medicines. Supportive stance of the doctor, support from family members and faith in the efficacy of the treatment seemed to be associated with treatment completion.

### **6.2.3 Pilot Project Site**

The second part of field investigation was carried out at the site of a successful pilot project. The field functionaries extended full cooperation.

In this phase, in addition to the district tuberculosis officer, health workers (40), tuberculosis supervisors (2), pharmacists (2), doctor and the other PHC staff, 35 tuberculosis patients were contacted.

#### **6.2.3.1 Patients**

Patients included 6 who had completed the treatment, 20 who were undergoing the treatment and 9 defaulters. Their attitudes and experiences were by and large similar to those of patients in the urban areas. Compared to other categories, defaulters had much less faith in the effectiveness of medicines. They complained of adverse side effects much more than the patients who were undergoing the treatment and those who had been cured. Patients reported fear of death, concern about their children, loss of interest in work, insomnia, unwillingness to discuss their condition with others, anxiety about infecting dear ones as some of their major worries. Family members and relatives were a source of tension as well as support.

In rural areas, surprisingly, people were much more willing to talk openly about their disease than the urban respondents. They experienced adverse reactions of community members to their having contracted tuberculosis, but the intensity and fear of social stigma appeared weaker in rural areas.

However, patients quoted instances when people started avoiding them on their contracting tuberculosis. Two patients mentioned that they concealed this information from others.

Regarding drug delivery, patient experiences were mixed. Thirteen patients reported that they were administered the drugs at home thrice weekly; nine patients observed that the health worker visited them once a week to give the week's supply and the remaining reported that they had to go the PHC to collect their medicines. To chronic patients, those who lived near the PHC or were too ill to walk, medicines were delivered at home.

Reasons for default were similar to the ones given by urban patients: a feeling of improvement; negative side effect of drugs; and, economic problems. One patient mentioned no improvement in condition coupled with adverse side effects as the reason for default. Probably poor nourishment aggravated the side effects. Like their urban counterparts,

patients were unaware that improvement in condition did not mean cure and that incomplete treatment would compound their problem.

None of the patients mentioned that the health worker administered the drug to the patient in his/her presence. Several patients observed that there was no fixed time for the health worker's visit. The visit was made at an hour convenient to the health worker. Some of the patients were not clear about guidelines for taking drugs.

The Social Welfare Department has a scheme to pay a certain amount of money to poor patients of tuberculosis every quarter to provide nutritional support. But the procedures for obtaining that help are so bureaucratic and tedious that even though most patients were aware of the scheme, only three availed the benefit.

### **6.2.3.2 Health Workers**

As the main link between the health delivery system and the community in rural areas, Health Workers (HW) play a crucial role. In a programme like the RNTP which requires regular interaction between the health care provider and receiver for a duration of 6-8 months, the contribution of HWs becomes significant, particularly for case holding. It was therefore important to understand the priorities, perceptions, and problems of HWs. We contacted 40 HWs for this purpose.

When asked how many times they visited tuberculosis patients, 32 HWs reported thrice a week and 8 mentioned once a week. The time given for tuberculosis work ranged from 15 minutes per week (9 respondents), to 30 minutes (15), 1 hour (11) and more than 1 hour (5). Likewise, 29 workers mentioned filling the patients' cards thrice a week and 11 mentioned doing so once a week. As these responses could get affected by social desirability considerations, we will return to these later.

When asked what do they do to motivate defaulters, HWs mentioned a variety of tactics. They mentioned guiding, persuading and counselling the defaulters, giving more information about tuberculosis, bringing pressure on patients from the village head (the Sarpanch) to resume the treatment, and discussing the problem of default in group meetings. While giving the medicines, 33 HWs trusted the patient, 5 reported explaining the details to a sensible family member and 2 indicated trusting an educated member of the family.

Regarding their experience of dispensing medicines at homes, 22 thought it to be a positive one. Some others mentioned that they felt sorry for the patient, tried to provide care with love, were concerned that the patient should get well soon, thought home supply of medicine benefitted the poor patients and ensured regular drug intake.

Major frustrations for HWs included having to waste a lot of time in going to far off places to reach patients, nonavailability of patients at home, the fear of contracting the disease themselves, difficulty in dealing with uneducated patients and those who do not understand instructions, initial difficulty in establishing rapport with patients, and their patients turning defaulters. Some of the HWs suggested that patients should come to the PHC to collect their

medicines. Home delivery diminished patients' initiative : they thought that HWs were paid extra to visit the patients and they themselves became passive. This made patients indifferent and irregular in taking the medicine. According to some HWs, abolishing home visits would reduce their own workload by 25%. A few HWs mentioned that defaulters made them sad because that indicated the futility of their efforts.

Many HWs thought that visiting patients, giving them tuberculosis drugs, and seeing them recover was a rewarding experience. It gave them a sense of fulfilment. They combined the tuberculosis visits with other health-related work. Patient recovery enhanced their credibility for other health care activities, and people appreciated their contribution to the community.

Regarding the possibility of incentive for tuberculosis work to motivate HWs, interestingly 18 HWS thought that it would not serve any purpose. Others thought that if the government gave any monetary incentive they would accept it. Five HWs thought that some kind of incentive would be welcome as it would increase their enthusiasm and sense of responsibility. For improving the health care delivery, HWs had a variety of suggestions:

- There should be a separate worker for tuberculosis for population of 20,000.
- HWs should be given long-duration training so that they can provide adequate information to patients and help them suitably.
- Camps should be organised at the village level to give health education to community.
- HWs should be given economic incentives.
- Seniority-wise incentive system should be developed for workers, senior workers, head workers etc.
- Steps should be taken to protect TB workers from contracting the disease. In case HWs contract TB, they should be given special attention and treatment.
- TB workers should be given soap, napkin, and a bag for carrying the medicine.
- Tuberculosis workers should be given certificates.
- Help of Anganwadi workers or village teachers should be sought in reaching patients. Educated unemployed youth should be recruited as motivators.
- Patients should be given economic support. (Mentioned by majority of HWs).
- Patients should be given nourishment (milk, fresh fruits, etc).
- Patients should be given transport or the mobile lab facility.
- Patients and HWs should be given health education by using audiovisual methods.

- In addition to the DTC, sputum test should be carried out at the PHC also.
- There should be monthly TB OPD camps in every village.
- TB project should be a vertical programme.
- Providing motivation to TB patients at the PHC would reduce default rate by at least 15%.
- The quantity of drugs should be reduced and quality should be improved. (several respondents).
- Medicines should be delivered at home only to bedridden patients.
- Patients who go out for paid regular work should be given all the medicines together.

The above suggestions which were spontaneous indicate the HWs' concern for their patients, and their positive as well as frustrating experiences.

However, these responses also betray a lack of comfort among the HWs with their own level of knowledge about tuberculosis, an admirable openness on their part in acknowledging their need to be equipped with more technical inputs, and their high concern for patient education. Clearly, this emphasises the need for extensive awareness building and educational campaigns. A few recommendations such as reducing the drug dose in the standard regimen because of adverse side effects on patients suggest considerable empathy and concern for the patients. They also indicate HWs' technical naivete in suggesting simplistic solutions, thereby confirming their own recommendation that their training should be strengthened.

There were some responses of HWs that did not confirm assumptions and expectations about the implementation of the programme. These are presented below:

- We should be allowed to visit patients once-a-week; thrice-a-week visit is not possible.
- Because of other work and laziness, we do not go as regularly as expected.
- Because of other responsibilities, we cannot do the follow up regularly.
- Because it is not possible to visit several villages in the same day, the medicine should be distributed at a central place.

In interviews, tuberculosis supervisors also acknowledged that because of far-off location of villages, and other health care responsibilities, HWs are not able to visit patients thrice a week as expected.

When asked why they do not visit their patients three times a week, 27 HWs reported that they trust their patients and know that patients would take drugs regularly; four observed that they do not go so frequently for fear of contracting the disease; and, only one mentioned that he did not have enough time. Significantly, eight HWs mentioned that they do not go frequently because patients themselves do not like the HW visiting them often. Some workers mentioned that from time to time some programmes such as immunisation or eye donation become more important. As HWs are expected to pay greater attention to them, existing work and responsibilities such as Tb work suffers. These responses thus highlight a gap between programme expectation and actual implementation. For a programme with supervised drug administration as an important component, this is an important feedback.

Likewise, it was found that card filling was not regular: some health functionaries tended to fill all the blank cards pertaining to several months in one go.

These departures suggest that the implementational realities are at times at variance with the intended practices and procedures, and an important element in improving programme performance is to acknowledge that not all assumptions incorporated in the design need be valid at the field level. In exploring the experiences and perceptions of important stakeholders at the grassroots delivery point, the above anomalies came to light, and we believed that it would be useful to take cognizance of them.

## **7. SUMMARY AND CONCLUSIONS**

The purpose of our study was to explore the existing priority attached to tuberculosis by some of the key stakeholders and to understand factors that influenced the priority. It was found that tuberculosis enjoyed a modest-to-low priority compared to other diseases and health care programmes, at the central government level, in the media, and in the minds of doctors and other health care functionaries. A major factor probably could be the nature of disease itself which though contagious does not manifest itself in an epidemic form to compel urgent political and popular attention. Also the long-duration regimen for treatment does not make the programme easily amenable to a focused and aggressive initiative in a project mode, as could be achieved in cases like small pox eradication. Socially, a variety of outdated misconceptions about the disease still persist in the minds of the common public. Media is not yet inducted in the war against tuberculosis: despite the rising cases of HIV-TB coinfection in the country, and the growing incidence of the multi-drug resistant strains of tuberculosis, the disease receives almost nil attention in the print and powerful electronic media.

However, major reasons for perceived low priority seem to be internal to the RNTP. For want of uninterrupted dedicated leadership at the top, despite a sound design, the programme has not made the expected dent. Inspired leadership can provide both direction and energy. At the delivery level, medical doctors and other functionaries do not attach a very high priority to TB. There seems to exist a gap between programme design and implementation. Although the design is fairly detailed, not enough scope nor support seems to be available at the delivery level for local adaptation, ingenuity and innovation. Also the programme structure of the past has not responded to new realities; major players like private practitioners and NGOs are not involved

meaningfully. As a result, the energy of the private sector and the commitment of the NGOs have not yet been roped into the national tuberculosis programme.

## 8. ACHIEVING GREATER EFFECTIVENESS: SOME SUGGESTIONS AND ILLUSTRATIVE STEPS

1. We had observed at the beginning of this report that to us a very important stakeholder is the community at large. People need to be informed that with modern drug therapy, TB is no longer the curse it used to be regarded earlier. The programme managers owe a heavy responsibility to educate this category of stakeholders about the basic truths about manageability and curability of TB. Such education will help people overcome their misconceptions and primitive fears which sometimes lead to social stigmatisation of patients even by their own family members. With the availability and popularity of the electronic media in the country, mounting imaginative awareness-building programmes may not be difficult. At an experimental level, awareness-building for tuberculosis can even be integrated with other social programmes with extensive outreach such as literacy.
2. An important subset of the larger community, and to us THE most important stakeholder for the tuberculosis programme is the patient. It is true that in the RNTP, care has been taken to provide medical and emotional support to the patient from diagnosis to treatment to cure stage. Many of our patient respondents mentioned receiving information regarding tuberculosis from their doctor as well as the health workers. Yet several respondents expressed ignorance about two vital facts: that symptomatic relief is not cure; and that interruption of treatment can develop resistance and complications, and therefore **TREATMENT, THOUGH LONG, SHOULD BE COMPLETED**. Defaulters also expressed lack of faith in the drugs. These important points prominently appear in the District Tuberculosis Programme Chart on Motivation as part of initial motivation by the Medical Officer, and therefore are most probably being conveyed to the patients, but evidently are not being registered by many of them. Given the importance of these factors for complete recovery, it is suggested that massive patient education campaigns can be launched in the mass media. It may be possible that doctors do not emphasise strongly enough the negative consequences of default for fear of scaring their patients. However, sharing basic truth with patients in a reassuring way can indeed arm the latter with important knowledge so they can combat the disease more effectively. Media, particularly electronic media, needs to be utilised extensively for patient education, including information on early symptoms, where to go for diagnosis, availability of free treatment, etc. Additionally, for moulding community attitudes not only towards the disease but also towards patients, education of people about the importance of emotional support from family in patient recovery should be an integral part of awareness-building.
3. For enhancing the **PERCEIVED** priority of tuberculosis in the country, the **REAL** priority has to move up. This means that in their thoughts, and actions, the key decision-

makers NEED to attach visible importance and urgency to the programme. This can be done through a variety of verbal and nonverbal signals.

4. As mentioned earlier, frequent changes in the top leadership in the past are likely to have sent confusing signals to the programme administrators and implementors at various levels. To convey its seriousness in supporting the RNTP, it is imperative that the government ensures an uninterrupted tenure of the incumbent holding the key position of the DDGTB.
5. For a broader and more effective coverage, private practitioners and NGOs have to be involved. Several studies have brought out the need to do so.
6. The programme in its present form does not offer sufficient scope for local innovations. Programme flexibility and effectiveness can be increased at the delivery level if managers at the field level can be empowered to incorporate innovative practices based on local conditions which are consistent with the overall programme objectives.
7. In a very simple way, the national programme can be made more meaningful at the delivery level, if the patient identity cards and the tuberculosis treatment cards can be made available in the state language instead of being in English. This would facilitate record keeping for programme functionaries at the grassroots level, many of whom may not be highly conversant with English. It would also help the patients. Cards in their own language may serve to ACTUALLY communicate to literate patients the points mentioned in 2. above which are printed on the identity cards being carried by patients, but, ironically, are NOT KNOWN to patients. Such cards may serve a variety of functional purposes for which they are meant, for example, reminding patients about appointment dates. Being in English, the present identity cards have limited usefulness for most patients.
8. For enhancing the perceived priority of tuberculosis at the delivery level, programme managers can think of suitable recognition for good performers. If financial incentives can create problems of parity and equity vis-a-vis other health care programmes, alternate approaches can be thought of. For example, methods like certificates honouring dedicated programme workers, public felicitation in annual functions by local community leaders, interviews with popular workers on the local television can help immensely in conveying a message that their work is important and is appreciated by a grateful community. Instead of developing a standard nation-wise scheme for such rewards, the implementational details can be decentralised and local initiative and creativity can be inducted to work out details.
9. If the NRTP has to be successful, it has to be made people's programme. In the process, if it loses part of its monolithic structure, and acquires slightly different regional identities in different regions, all subservient to the overall programme objectives but adapted to local conditions and requirements, it can be much more effective. At state and district levels, besides the government agencies, other stakeholders such as private practitioners, medical associations, NGOs, local industry, the media, concerned citizens

and opinion leaders, educational institutes, and public at large can be involved in evolving workable approaches and in their implementation. A number of government departments and services in the country such as railways and post have started seeking the involvement of public in a variety of fora, to improve their own functioning. And their experience has been positive. If people sense commitment, persistence, and an earnest invitation to contribute in such efforts, they respond! A similar approach needs to be adopted in the area of public health in general, and tuberculosis in particular. The problem of controlling tuberculosis is not simply the concern of the central and state governments alone, it touches all the citizens personally and metaphorically. Therefore, they have to be made to "own" this national concern and need to be enrolled as active participants. Design for such involvement also can be involved jointly through consultation and dialogue.

10. It is a common experience that in government programmes, the initial phase of the programme when funds have to be sought and project details formulated, there is high energy and enthusiasm in all the functionaries. As the programme moves to the implementation phase, the interest begins to wane and the earlier momentum begins to give way to complacency, and indifference. For better energisation of the system, the donor agencies can think of splitting the total intended assistance so that subsequent instalments have to be earned afresh based on the past performance. This would put pressure on recipients to sustain high priority and performance.

Independent committees can be constituted by the donors to monitor different facets of programme implementation. Such external evaluation can be more frequent than periodic reviews undertaken by the government. Also, survey by an independent committee can capture field realities more meaningfully since respondents do not feel obliged to give the "expected" set of replies which can reduce the dependability of government-sponsored surveys. Provision for such monitoring can be included at the project formulation stage.

Specifically in the case of the GTP, if there is high concern about putting pressure on the government for programme delivery, media can be involved in informing people about the incidence of tuberculosis in the country, the looming threat of coinfection, and how in some countries, the experience with DOTS has been very positive. A professional communication agency can be commissioned for this purpose. Of course this needs to be done with great sensitivity so as not to belittle the enormous efforts put in by the government machinery into the RNTP, nor to hurt national sensibilities, but to make people aware that with concerted effort a lot can be achieved and that they can expect and demand a certain level of service from the government. The main thrust can be that for the people and the government the time to act is now.

#### ACKNOWLEDGEMENTS

For carrying out this project, a number of people were contacted who readily shared with me their perceptions, experiences and view points. I wish to place on record my appreciation for all their help. First and foremost, I am grateful to all our respondents including doctors, health

workers, supervisors, and tuberculosis patients for their generosity in talking frankly to us about their experiences. Their names are not mentioned for reasons of anonymity.

I benefitted from discussions with the senior and top officials in the Ministry of Health, especially in the Tuberculosis Directorate. Officials met included Mr. P.S.Bhatnagar, Additional Secretary Health, Dr.K.K.Dutta, formerly with the Tuberculosis Directorate and currently Director, National Institute of Communicable Diseases, New Delhi, Dr. Rohit Sarin, Consultant to the Tuberculosis Division, New Delhi, and Dr. Khanna, New Delhi Tuberculosis Centre. Dr. Nagpaul, Tuberculosis Association of India, Dr. Pamra, consultant, Tuberculosis and Chest Diseases, New Delhi, Dr. Mukund Uplekar and Dr. Sheela Rangan, Foundation for Research in Community Health, Mumbai gave freely of their time. Closer home, Dr. BM Soni, Assistant Director Tuberculosis Directorate, Gandhinagar, Dr. RK Jadhav and Dr. Chhaya at the Tuberculosis Demonstration and Training Centre, Ahmedabad and Dr. Parmar, Project Officer, RNTP Pilot Project, Mehsana provided first hand account of various aspects of managing the diagnosis and treatment of tuberculosis at the field level. Additionally, a number of people were interviewed informally to solicit their perceptions and experiences about the management of tuberculosis. I place on record my gratitude to all of them. Lastly I am thankful to Dr. Dileep Mavlankar, Professor Subhash Bhatnagar, Mr. Ashok Joshi, Mr. Narendra Makwana, Ms. Renu Misra and Ms. Barathi for their help in this project.

**REFERENCES**

"Operational Guideline for Revised National Tuberculosis Control", Directorate General of Health Services, Nirman Bhavan, New Delhi, 1995.

"Technical Guide for Tuberculosis Control", Directorate General of Health Services, Nirman Bhavan, New Delhi, 1995.

Pamra, S.P. (1995), "The Role of Voluntary Organizations in Tuberculosis Control", (eds.) A.K. Chakraborty, Sheela Rangan, and Mukund Uplekar. Urban Tuberculosis Control: Problems and Prospects, Bombay: The Foundation for Research in Community Health, pp. 61-67.

Ray, Indranil Basu, (1996), "Still on the sick bed", The Sunday Times of India Ahmedabad, Sep. 8.

Uplekar, Mukund (1995), "Private Doctors and Tuberculosis Control", (eds.) A.K. Chakraborty, Sheela Rangan, and Mukund Uplekar. Urban Tuberculosis Control: Problems and Prospects, Bombay: The Foundation for Research in Community Health, pp. 77-82.

Uplekar, Mukund and Rangan, Sheela. (1996), Tackling TB: The Search for Solutions, Bombay: The Foundation for Research in Community Health.

Appendix - 1**Questionnaire for Government Doctors****Personal Details**

Name :  
 Age :  
 Sex : Male/Female

Professional qualification:

Designation or Professional category: Private GP/Private  
 Consultant/Government/AMC  
 Doctor

Work Experience (No. of years):

1. Listed below are some common diseases. In your perception, how do these diseases rank in terms of their impact on public health? Rank from 1 to 7, giving rank 1 to the most important, 2 to the next important, and rank 7 to the least important according to you.

Rank

- \_\_\_ a) AIDS  
 \_\_\_ b) Leprosy  
 \_\_\_ c) Tuberculosis  
 \_\_\_ d) Malaria  
 \_\_\_ e) Diarrhoeal diseases  
 \_\_\_ f) Heart disease  
 \_\_\_ g) Jaundice

2. Please indicate if the government at the **state** level is conducting any specific programmes for control of the above-mentioned diseases? If yes, then for which diseases in particular? Please rank them in order of the priority you think the **state** government attaches to these diseases. Please give rank 1 to the disease with the highest **state** level priority, rank 2 to the next one, and so on, with rank 7 to the disease which in your opinion receives the lowest priority from the state (central) government.

**Important :** While giving ranks, please do not give the same rank to two diseases.

Rank

- \_\_\_\_\_ a) AIDS
- \_\_\_\_\_ b) Leprosy
- \_\_\_\_\_ c) Tuberculosis
- \_\_\_\_\_ d) Malaria
- \_\_\_\_\_ e) Diarrhoeal diseases
- \_\_\_\_\_ f) Heart disease
- \_\_\_\_\_ g) Jaundice

3. Please indicate if the government at the **central** level is conducting any specific programmes for control of the above-mentioned diseases? If yes, then for which diseases in particular? Please rank them in order of the priority you think the **central** government attaches to these diseases. Please give rank 1 to the disease with the highest **central** level priority, rank 2 to the next one, and so on, with rank 7 to the disease which in your opinion receives the lowest priority from the central government.

Rank

- \_\_\_\_\_ a) AIDS
- \_\_\_\_\_ b) Leprosy
- \_\_\_\_\_ c) Tuberculosis
- \_\_\_\_\_ d) Malaria
- \_\_\_\_\_ e) Diarrhoeal diseases
- \_\_\_\_\_ f) Heart disease
- \_\_\_\_\_ g) Jaundice

4. According to you which 5 diseases should be accorded the highest priority by the central and state governments today? Please indicate your order of priority with rank 1 as the highest priority.

<u>Rank</u>	<u>Name of the Disease</u>
1)	_____
2)	_____
3)	_____
4)	_____
5)	_____

Please explain why do you give high priority to the disease you have chosen as No. 1.

5. In your belief, which organisations are doing useful work in the area of disease control?  
Govt dispensaries and PHCs/ NGOs/Private practitioners.
6. According to you, which are the three most important government programmes undertaken currently towards disease control and for which diseases?

Appendix - 2

**Questionnaire for TB Patients**

Name : Male/Female:

Address : Age:

No. of family members: Male: Female:

Occupation :

Income :

Details of TB treatment:

Diagnosis :

Treatment :

Extent of hospitalisation :

Duration of treatment :

Experiences in the hospital :

Experiences in taking the treatment :

Faith in medication :

Side-effects of drugs :

Personal attitude towards TB :

Family and communication reactions to TB:

Financial problems:

Loans for treatment :

Amount :

Experiences in reaching the hospital :

Sources of information about TB\*:

Mass Media

Community

Own Experience

Public Health Services

Formal Education

Private Doctors

Can't say

\* Borrowed from Uplekar, Mukund and Rangan, Sheela. (1996), Tackling TB: The Search for Solutions, Bombay: The Foundation for Research in Community Health.

For defaulters:

Reasons for default:

- Felt Better
- Economic Problems
- Unforeseen Problems
- Health Services related problems
- Got bored of treatment
- Side effects of drug
- Don't remember
- No improvement in condition

Any other comment:

\* Borrowed from Uplekar, Mukund and Rangan, Sheela. (1996), Tackling TB: The Search for Solutions, Bombay: The Foundation for Research in Community Health.

Appendix - 3

**Questionnaire for TB Health Workers**

Name : Male/Female:

Address : Age:

Area covered (no.of villages): No.of patients:

No. of visits per week: 3 / 2 / 1

Are you welcomed : Yes / No / Some times

Percentage of time devoted to TB per week:

No. of times the patient card is filled in a week: 3 / 2 / 1

What do you do for defaulters?

In giving drugs whom do you trust? The patients / elders / matured family members / educated family members.

Experiences in dispensing drugs:

Difficulties experienced:

Reasons for not visiting patients thrice a week:

Feeling towards tuberculosis work:

Views on the present system.

Suggestions for improvement.